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Braving Uncertainty in the Quest for a Cure: Cancer Care Access During the COVID-19 National Lockdown

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BRAVING UNCERTAINTY IN THE QUEST FOR A CURE: CANCER CARE ACCESS DURING THE COVID-19 NATIONAL LOCKDOWN

Abstract: This paper examines cancer care access during the nationwide lockdown due to COVID-19 in two states of India's northeast. A semi-structured interview was conducted by purposive sampling of fifteen participants with cancers of the oral, lungs, stomach, breast and cervix, six key informant oncologists and four Non-Governmental Organizations (NGOs) facilitating cancer services. Ethical clearances were received from the study institutes. The data was coded and transcribed verbatim on emerging themes. The emerging themes were treatment delay, financial constraint, alternative medicine and bridging gaps by NGOs. Whereas, if financial status hampered access, harassment on availing care was encountered with choosing herbal medication in fear of chemotherapy, surgery and testimonials of relatives. However, support through NGO collaborations enhanced care efficiency for the health systems and cancer patients alike during the challenging times due to the COVID-19 pandemic. Lessons learnt during the COVID-19 pandemic extend beyond the functioning of a robust health system. Collaboration via sectors became pronounced during this uncertainty, thus, emerging resource pooling and zeal to take charge of one's health. Cancer institutes could magnify these lessons on strengthening health systems for combating unforeseen pandemics.

Keywords: cancer, COVID-19, India

Introduction

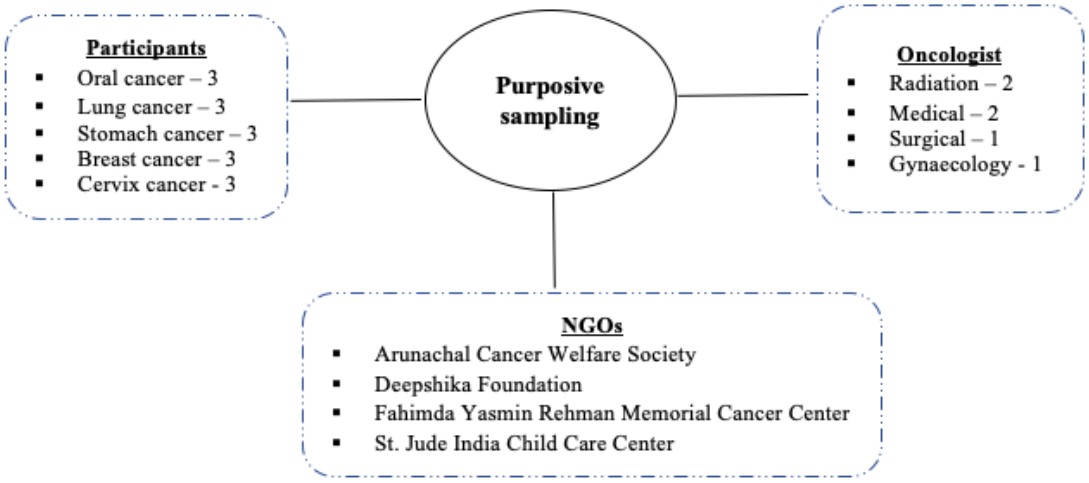
The unprecedented outbreak of the COVID-19 pandemic affected all spheres of health systems. Global evidence showed a significant delay in cancer diagnosis, with estimates projecting numbers of preventable deaths. An assessment (Lai *et al.*, 2020) conducted from the population-based health records of Ireland, England and the USA showed a 45-66 per cent reduction in admissions for chemotherapy and 70-89 per cent emergency referrals compared to the pre-COVID pandemic. Similarly, in a cohort study in India (Ranganathan P, Sengar M, Chinnaswamy G *et al.*, 2021) there was a reduction in cancer services such as a 54 per cent reduction in new cancer admission, follow-up reduction by 46 per cent, hospital admission by 36 per cent, surgeries by 49 per cent with 25 per cent reduction of cancer screening. Several reports (Gordon Wishart, 2021; Boyles, 2020; Hewgill, 2022) highlight an increase in advancing cancers due to delays in diagnosis and timely treatment.

Adding to the shortage of cancer services was the conversion of existing hospitals into COVID centers. Low- and Middle-income countries (LMIC) face a challenging situation considering their health systems are already under tremendous pressure. An expensive lesson from the COVID-19 pandemic is that the rise in the prevalence of cancer in the LMICs, when combined with public health failures, renders the affected populations more vulnerable to health emergencies (Teoh *et al.*, 2022). In India, studies found there was reduced cancer screening, diagnosis and treatment (Pareek, A., Patel, A. A., Harshavardhan, A., *et al.*, 2021; Mitra, M., & Basu, M., 2020). This paper attempts to understand the phenomenon of cancer care access during the global crisis of the COVID-19 pandemic.

Method

This study followed a purposive sampling method for semi-structured interviews, see figure 1. A total of 25 interviews were conducted comprising 15 cancer patients (oral, lung, stomach, breast and cervix), six oncologists (radiation - 3, medical - 2, surgical - 1 and gynecology - 1) and four NGOs working at the state level for cancer service facilitation. Each interview ranged between 20-30 minutes; it was recorded and transcribed verbatim on emerging themes. The informed consent form and participation information sheets were available in English and Assamese. The data were coded and analyzed using MS Word version 16.16.27.

Figure 1: Study methodology



Results

The emerging themes were: (i) treatment delay, (ii) financial constraint, (iii) alternative medicine, and (iv) bridging gaps by NGOs.

Theme one: treatment delay

Participants expressed delay in getting timely treatment for cancer due to the nation-wide lockdown announced for COVID-19. A 30 years old woman from Arunachal Pradesh, a homemaker with oral cancer, shared her ordeal:

> "I had a lump on my tongue for which I visited the Medicine Specialist in a CHC who told me a biopsy for diagnosis confirmation is required. He referred me to the state medical college in Naharlagun, a red zone at that time. My husband and I drove our vehicle and somehow reached to get the biopsy done in a private lab. It took around 15 days for the reports to come, which confirmed oral cancer. Since there was a shortage of infrastructure in our cancer hospital, we were referred to Guwahati. But, because of the lockdown, it took around four months to get myself operated on in Guwahati. The doctors operated to remove parts of my tongue, and grafting was done from the forearm and thigh.

Similarly, a 32 years old man, a police constable with stomach cancer from Arunachal Pradesh said:

> "I blame the coronavirus as I am a police officer, and I had intense duty to attain because of which I could not take my gastric medicines properly. I was recently transferred from the district to the capital for COVID-19 duty, and due to strenuous work, I eventually developed a stomach ulcer. Had it been a regular time, I would have got respite to take care of myself and this situation of having stomach CA would not have reached".

Theme two: financial constraint

While several participants had run short of money to finance their treatment in another city. The lockdown due to COVID added a constraint on prioritizing their expenses for travel to return home over their cancer treatment. A 60 years old man, a school teacher with lung cancer from Assam, said:

> "After my diagnosis was confirmed in Assam Medical College in Dibrugarh, my family took me to Apollo Chennai for cancer treatment. It was a struggle to arrange money during the COVID, so we decided we would return home. I returned home but did not continue my cancer treatment due to a shortage of money spent planning for my return. My condition deteriorated, and I resumed treatment one to two months after the first lockdown was lifted up".

Participants visiting from the districts to the cancer institute in the state's capital struggled to pay for diagnostic tests, accommodation, transportation and food. Due to the isolation protocol, those who travelled for chemotherapy with their family often were not together. A49 years old woman with breast cancer, a homemaker, shared:

> "When we reached Guwahati for chemotherapy, my husband was isolated in the COVID centre for fifteen days, while I had to go alone to the hospital for chemotherapy. I was depressed during those times".

Theme three: alternative medicine

Testimonials from relatives, friends or acquaintances on the benefits of herbal medicines, homoeopathy and Ayurveda motivated few to prefer it over conventional cancer therapeutics. Another reason was fear of surgery and chemotherapy's effects, which led to these choices. Those participants who tried these alternative therapies had to prolong their intake during the COVID lockdown as no other treatment choice was available. For example, a 54 years old male, self-employed from Arunachal Pradesh, said:

> "We did not want to get the surgery, so we looked for alternatives. We heard from a relative that there is an ex-horticultural officer in Pasighat (Arunachal Pradesh) who gives herbal medicines for cancer cures. So, we went to this lady to seek advice. I started taking medicine sometime in February 2020, and then by March 2020, the lockdown was announced, and we got stuck in Pasighat after that. I did feel alright during those times. However, the unbearable stomach pain returned, and that is when my family decided that I should get proper cancer treatment for my stomach cancer".

All the key informants found it particularly challenging when patients came at a late stage of cancer following experimentation with different therapies. A Radiation Oncologist with three years in service highlights it as:

> "The patients also use alternative un-proven treatment is also utilized by the patients. Few of the patients prefer local treatment or seek herbal treatment, which has been responsible for delay in treatment for many patients".

Additionally, the request to the doctors by the patient's attendant or relatives to keep the diagnosis a secret from the patient was a challenge. This was confirmed by the key informants, for example a Medical Oncologist for fifteen years in service said:

> "The relatives of the patient would often request us to withhold the diagnosis to the patients as the word "cancer" itself will demoralize them. It is challenging for us since we have to disclose and take the patient into confidence for a fulfilling and informed cancer treatment."

Theme four: bridging gaps by NGOs

The key informants confirmed cancer patients face difficulties, such as getting a consultation, diagnostic tests and other targeted therapies. A medical oncologist also stated:

> "We usually administer chemotherapy in the hospital. But, during COVID since it was an extraordinary circumstance, we issued doses of chemotherapy to the patient's attendant so that it can be administered in a facility closer to where they live".

Collaborations between the cancer institute and NGOs strengthened due to the requirement of transporting cancer patients for cancer services and the deceased to their homes for the final rites. Another Radiation Oncologist in service for 16 years recognized the services extended by the NGOs during COVID lockdowns:

> "Staff from the NGOs volunteered to maintain social distancing, food and clothing distribution and treatment financing for those who could not afford it. The support of the NGOs goes a long way for patients to get the corrective and timely cancer treatment".

The mode of operation had to be tweaked as per the COVID protocol. For example, the residents' occupancy was reduced to fifty per cent, as the staff of an NGO mentioned.

> "Due to COVID, we have reduced the accommodation capacity to 50 per cent. We arrange their stay in a hotel for those children who come to us for their maintenance dosage. As we cannot frequently get the children to undergo COVID tests just for a few days stay in our center for the patients' convenience".

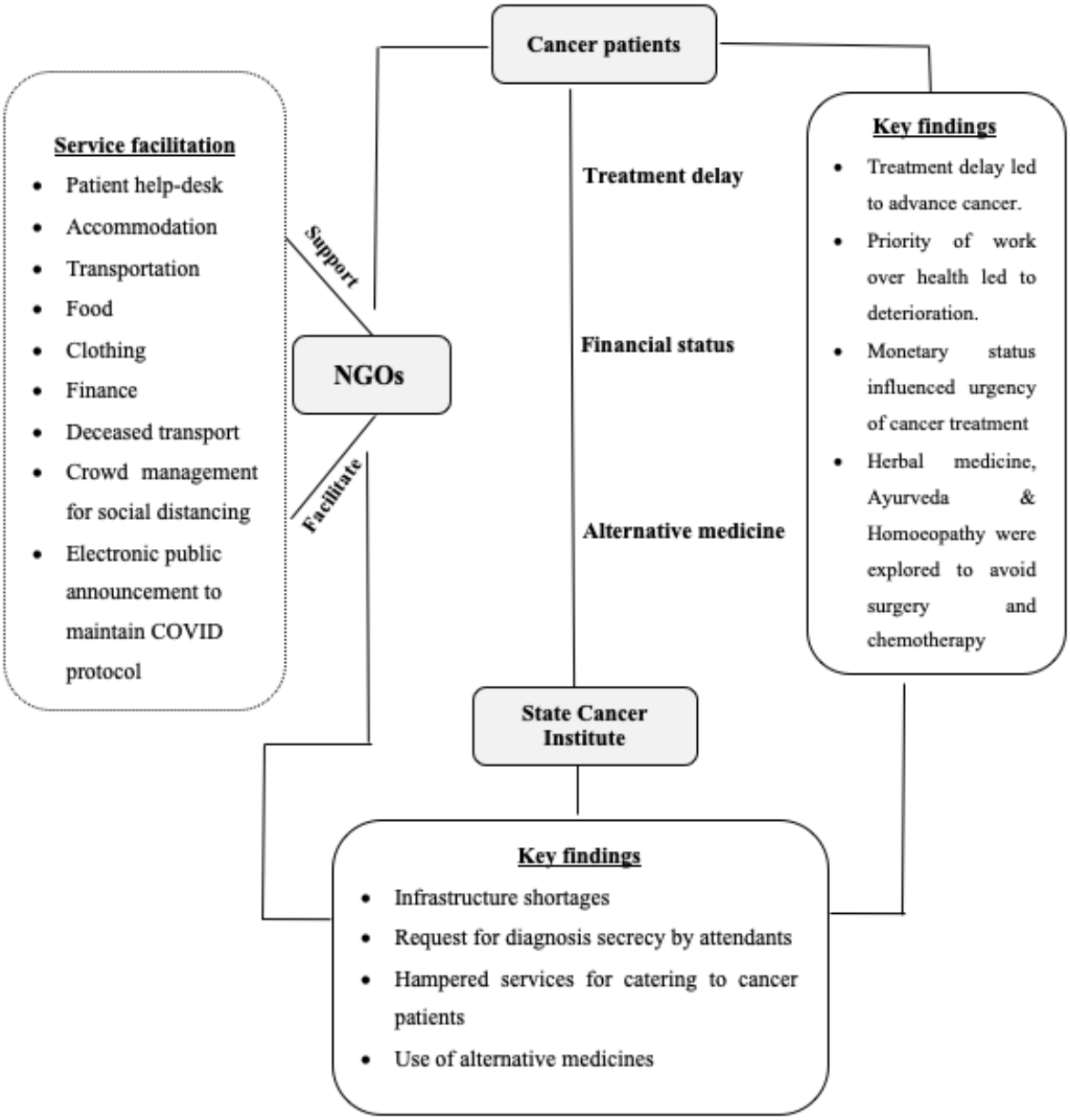
However, another NGO continued to provide its services for patient support from its help desk in one of the study institutes, as stated by the member secretary of another NGO:

> "So, all these cancer patients who have taken shelter here, their food and transportation are free. We don't charge a penny here. Even in our Hospice center, we give them free ambulance services within 40 Km. Everything is free there, like taking them from the hospital to the Hospice center and providing them with food. This facility is for patients from all over the country. This center has patients from Arunachal, Mizoram, Manipur, Tripura and Odisha".

Another NGO providing palliative services in collaboration with one of the study institutes, to which its chairman said:

"We were told that there are financially poor patients who come to the hospital and find it difficult to transport the dead body of the deceased to their respective villages. So, we stepped in to run a scheme in partnership with the hospital to transport the deceased to their homes which continue post-COVID lockdowns too".

Figure 2: summary of quest for cancer care during COVID-19 pandemic



Discussion

The guidelines for cancer care during disaster situations in LMICs seem to be heavily focused on the delivery of cancer treatment, with far less attention given to other essential areas such as early detection, diagnosis, and delivery of supportive and survivorship care (Teoh, S.-P. *et al.* 2022). The findings in this paper highlight that the financial status of the participants was the driving factor in

deciding the urgency of availing of cancer treatment. However, in line with other research (Teoh, S.-P. *et al.,* 2022; Fuentes-Alabi, 202, and Bong *et al.,* 2020), this paper found the tremendous burden on the health systems to double up as a center for COVID management did affect the oncology services. Participants also reported delays in getting timely treatment leading to cancer stage advancement. The collaboration of the cancer institutes with the NGOs encouraged addressing gaps such as ensuring patients get on-time chemotherapy, surgery or other targeted treatment. This collaboration opens an opportunity for strengthening partnerships for efficient health systems delivery for cancer care (Carleigh Krubiner, 2020; World Health Organization, 2020). Constant engagement of the NGOs with the oncologists and medical social workers of the study area helped identify the interventions required and service delivery, especially for the socio-economically weaker population.

The lived experiences in the quest for cancer care bring the viewpoint of the patient and the provider on the challenges faced during the COVID emergency. Recognition of engagement with NGOs is a fantastic approach to supportive interventions in oncology. While disparities in health systems occurred, however, the adaptability and resilience of healthcare systems and healthcare workers globally, even as oncology services continued. (Global Health Research Group on Children's Non-Communicable Diseases Collaborative, 2022). Besides financial constraints, treatment delays were reported due to occupational workload and inability to take leaves. A survey (Papautsky, E. L., & Hamlish, T., 2020) amongst breast cancer survivors in the USA reveal a pervasive impact of COVID-19… a gap in disaster preparedness that leaves cancer survivors at risk for poor outcome and delays. Another cross-sectional study in Germany (Michalowsky, B., Hoffmann, W., Bohlken, J., & Kostev, K., 2021), found that the decrease in recognition of diseases was greater than the decrease in physician consultations. The findings of this paper are similar to a social media survey conducted in India (Kumari S., 2020; Khanna, D., Khargekar, N. C., & Khanna, A. K., 2020). found new paths were explored to mitigate the problems arising in cancer services due to the COVID-19 pandemic.

Conclusion

Lessons on oncology response during the pandemic draw attention to rethinking strategy, investment and policy rebuilding for continued cancer care during global chaos. Partnerships built between cancer institutes and NGOs for cancer services during the COVID emergency shape the future of efficient delivery of oncology care. Challenges emerging in this paper compel a revisit in addressing financial constraints faced by cancer patients via inclusive social security. At the same time, workplace policies should encourage employees to take charge of their health to build a culture without hesitation in taking a break for the personnel's health needs.

Limitation

This paper has several methodological limitations, such as the findings being confined to five cancer sites in a defined geographical location. There is scope for future research exploring the aftereffects of the COVID emergency. Keeping the socio-cultural diversity could bring insight into treatment-seeking behavior.

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